### Genetic Counseling Resources

#### Associated with Comprehensive Sickle Cell & Hemoglobinopathy Centers

Children's Hospital and Medical Center Odessa Brown Children's Clinic 2101 E. Yesler Way Seattle, WA 98122 Message: (206) 987-7290

Appointment: (206) 987-7232

Columbia Health Center 4400 - 37th South Seattle, WA 98118 Phone: (206) 296-4650

Mary Bridge Children's Hospital & Health Center

P.O. Box 5299

**Tacoma**, WA 98415-0299 Phone: (253) 403-3476

Prenatal Genetics Clinics (For pregnant women only)

Evergreen Hospital Maternal-Fetal Medicine 12040 NE 128th Street **Kirkland**, WA 98034 Phone: (425) 899-2200

Perinatal Medicine Swedish Medical Center 747 Broadway

**Seattle**, WA 98122-4307 Phone: (206) 386-2101

Prenatal Genetics and Fetal Therapy University of Washington Box 356159 Southly WA 98195

**Seattle**, WA 98195 Phone: (206) 598-8130

Obstetrix Medical Group of Washington, Inc. P.S. 314 Martin Luther King Jr. Way, Suite 402 **Tacoma**, WA 98405

Phone: (253) 552-1037

Obstetrix Eastside Maternal Fetal Medicine 1135 116th Ave. NE, Ste. 320 **Bellevue**, WA 98004

#### **General Genetics Clinics**

Group Health Cooperative Group Health University Center 4225 Roosevelt Way NE Seattle, WA 98105 Phone: (206) 634-4036

Services limited to Group Health members

University of Washington Medical Center Medical Genetics, Box 357720 1959 NE Pacific Street Seattle, WA 98195-7720 Phone: (206) 616-2135

Inland Northwest Genetics Clinic 2607 Southeast Blvd #A100 **Spokane**, WA 99223 Phone: (509) 535-2278

Madigan Army Medical Center Developmental Pediatrics **Tacoma**, WA98431-5000 Phone: (253) 968-2310 Services limited to Armed Services personnel and their dependents

Children's Hospital and Regional Medical Center P.O. Box 5371, 4H-4 4800 Sand Point Way NE Seattle, WA 98105 Phone: (206) 987-2665

University of Washington Biochemical Genetics Box 356320

**Seattle**, WA 98195-6320 Phone: (206) 616-1840 Fax: (206) 543-3379

Blue Mountain Genetic Counseling St. Mary Medical Center P.O. Box 1477 **Walla Walla**, WA 99362 Phone: (509) 525-1302

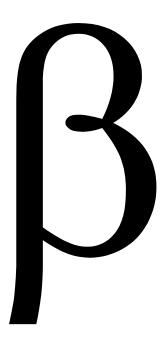
Central Washington Genetics Program Yakima Valley Memorial Hospital 2811 Tieton Drive Yakima, WA 98902 Phone: (509) 575-8160

Genetics Program Central Washington Hospital 1201 South Miller **Wenatchee**, WA 98801

Phone: (509) 667-3350



# Beta Thalassemia



Information for parents about beta thalassemia

# What is hemoglobin?

Hemoglobin is the part of blood that carries oxygen to all parts of the body. The usual type of hemoglobin is called hemoglobin A. Genes that we inherit from our parents determine what type of and how much hemoglobin we have.

#### What is beta thalassemia?

Hemoglobin is made up of different parts, including beta globin. Beta globin is produced by two genes and when one or both of these genes are not working properly the body makes less hemoglobin. This is called beta thalassemia and occurs in more than one form. One type of beta thalassemia cannot turn into another. Your child will have that type for his or her entire life.

## What is beta thalassemia major?

With this type of beta thalassemia, the genes produce very little beta globin, so the effect on the body is large, or major. This can be a very serious disease that will require regular blood transfusions and other medical treatments.

#### What is beta thalassemia minor?

With this type of beta thalassemia, the genes produce a larger amount of beta globin (still not enough) and the effect is minor. Although beta thalassemia minor does not cause any health problems, you and your baby's doctor should know that it can cause a mild anemia (low number of red blood cells).

# How does this affect the rest of our family?

Beta thalassemia is inherited, so you and other family members could also have beta thalassemia and may want to be tested. It is also important to know about your child's beta thalassemia status because future children in your family may be at risk for the same or a different type of beta thalassemia as this child. To have testing done, talk to your health care provider or one of the genetic counselors listed on the back of this pamphlet.

# What happens when beta thalassemia is inherited with other abnormal hemoglobins (like Sickle Cell)?

When a person inherits one gene for beta thalassemia from one parent and one gene for sickle hemoglobin (hemoglobin S) from the other parent it is called sickle-beta thalassemia. Sickle-beta thalassemia is similar to sickle cell disease and can cause serious health problems like painful episodes, fatigue, an enlarged spleen, and a higher risk for certain infections. E-beta thalassemia occurs when a person inherits one gene for beta thalassemia from one parent and one gene for hemoglobin E from the other parent. This is also a very serious disorder and will cause severe to moderate anemia. People with sickle-beta thalassemia and E-beta thalassemia should receive regular medical care.

### What do I do now?

We recommend that you and your partner have testing done to determine your hemoglobin status. This would provide you with information on your chances of having a future child with beta thalassemia major, sickle-beta thalassemia, or E-beta thalassemia. To have this testing done, talk to your health care provider or one of the genetic counselors listed on the back of this pamphlet. You may also want to share this information with the rest of your family. They may be interested in finding out their hemoglobin status as well.

## What can I do if I have more questions?

If you have more questions, you can talk to your child's health care provider or you can contact the Newborn Screening Program using the information below.

Newborn Screening Program 1610 NE 150th Street Shoreline, WA 98155 Phone: (206) 418-5534 or toll-free 1-866-660-9050 Email: NBS.Prog@doh.wa.gov

Internet: www.doh.wa.gov/nbs

